

CENTRE FOR HEALTH SERVICE DEVELOPMENT

Graduate School of Business

Building 29

University of Wollongong

Wollongong NSW 2522

Ph: (02) 4221 4411

Fax: (02) 4221 4679

Caring for Older Australians – Sydney 29/3/2011.

This presentation reflects on the body of work we have conducted over the past 15 years, through the evaluation of pilots, trials, demonstrations and new programs. It corrects the interpretation of our submission (# 343) and our comments are relevant to Chapter 4 on the framework for assessing aged care and Appendix B New aged care model options.

The summary of lessons we presented in our submission was that a system of common assessment tools for aged care are a bit complex but most of the necessary thinking and design work has been done. We know what to collect and when and can formulate ways of classifying and prioritising people as they enter the system and collecting the type of information that can help us assess outcomes.

There is a finite pool of data elements that can be used for different purposes and intake screening is designed to be used to differentiate between people who:

- Have no problems and need no services;
- Have minor problems (i.e., low need), need some services (e.g., meals, home maintenance), but do not need a full comprehensive assessment;
- Have medium to high needs and require a full assessment.

Figure 1 *Types of assessments and their different purposes and outcomes*

Type	Scope	Purpose/outcome
1	Determine eligibility	(1) Eligible or (2) Not eligible (may include referral elsewhere for a more appropriate service) Proceed to another type of assessment
2	Shallow and narrow assessment of need	Determine next steps, including any other assessments required (initial action plan) Prompt further assessment
3	Shallow and broad assessment of need	Determine next steps, including any other assessments required (initial action plan) Prompt further assessment
4	Deep and broad assessment of need (comprehensive assessment)	Care planning, potentially including clinical interventions
5	Deep and narrow assessment of need (specialist assessment)	Care planning, potentially including clinical interventions
6	Assessment of need for a specific service (service specific assessment)	Agency-specific service plan
7	Determine the relative priority of consumer need(s)	Priority rating derived from other assessments

These are not mutually exclusive types, with some assessments being a mix of two or three types. Reviews of screening and assessment tools in primary care, aged care, disability and carer support mostly relate to screening people living in the community who are seeking access to basic community health and support services. As a result they tend to have a broad focus that includes common problems in primary care, as well as screening for functional deficits that are common across many conditions.

It is fair to say we have resolved various complex client and carer assessment matters – resolved well enough to build the key design ideas (functional screening and carer assessment, priority rating) into State-wide systems in Victoria (Service Coordination Tool Templates) and Queensland with the Ongoing Needs Identification (ONI) tools and at national level with tools for care recipients (Australian Community Care Needs Assessment) and carers (Carer Eligibility and Needs Assessment).

Screening to find the right people for further assessment is a key entry point function. Carer assessment is an example of how this is done and how systems can be built that have good evidence behind them.

The Benevolent Society commissioned the University of Wollongong's Centre for Health Service Development (CHSD) to write one of its 'Research into Practice Briefings', on meeting the needs of carers. The Briefings bring together lessons learned from the literature on a topical issue in community care as a resource for those working in this sector. The aim was to distil key themes and messages from the research and to point to promising and innovative practices.

<http://www.bensoc.org.au/director/resources.cfm?action=search&keyword=carers&resourcetype=E4025FEAE43CB11ECE5A34EBF6A78203&resourcesubject=&submit.x=42&submit.y=6>

The material in the Benevolent Society/CHSD *Briefing Paper* on what works for carers started coming into focus around the end of the 1990s and into 2000 with the assessment of people for entry into the COAG-sponsored Illawarra Coordinated Care Trial. Carer status, along with the functional abilities of the care recipient, was a good predictor of need for coordinated care.

Then in 2002 the CHSD used that experience to design a priority rating system for NSW Home Care, using about 8000 encounters across the three main data collections, refining how the carer variables worked to assign priority for service delivery. Meanwhile in Victoria, South Australia, Queensland and NSW the work we did on assessment tools helped sharpen up what was useful to collect. The Victorian Primary Care Partnerships strategy used our work on Service Coordination Tool Templates (SCTT) to build a system that has now been going for about 10 years and has a continuous development cycle. The latest developments are not always as smart as we would like them to be but at least there is a strong policy and a consistent focus, the latest offering being 'Building blocks for improving continuity of care'. <http://www.health.vic.gov.au/pcps/>

In a national project in 2007-2008 designing the Carer Eligibility and Needs Assessment, CHSD expanded and clarified the useful initial assessment information on carers' needs for support, to collect it and put into an action plan and to prompt referrals. That was then the most recent in a series of about 10 linked assessment projects where the main link was the refinement of useful assessment questions, field testing them in real settings and learning along the way.

The next logical step after assessing is to work out what to do with what you know. In 2007 the Commonwealth Carers Section funded CHSD to do a *Review of Effective Caring*, where we climbed over a mountain of published studies and systematic reviews on carer needs and the effectiveness of interventions, analysed by the type of intervention and the type of carer and care recipient. The result was a report that was of door-stopper proportions (208 pages) that lives on the CHSD) <http://chsd.uow.edu.au/index.html> and DoHA websites (<http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-publicat-effective-caring-v1.html>); safe from easy accessibility by busy people who may find it useful, but only if they have a spare week or two.

The next step towards making the material more useful was an article on Lessons on Effective Caring in the journal *Family Matters* 2009 Issue No. 82 published by the Australian Institute for Family Studies (<http://www.aifs.gov.au/>). That article described the headline findings and outlined how we classified the material and weighed the strength of the evidence. We put our most recent ideas, along with advice on the practice implications, into the *Research into Practice Briefing* about how to work with carers. It was launched by the NSW Minister for Ageing and Disability Services on December 9 2010.

What the *Briefing* doesn't say, because we like to be polite, is that the sector is still suffering from a serious central policy vacuum, a dog's breakfast of competing programs, a strife of sometimes conflicting interests, and a large bank-up of un-met need. It is agnostic about the prospects for 'reform' as it is seen from Canberra.

But what still stands out since we started working in this area are the efforts of the agencies in the field, trying to make better sense of what they do in providing support services. The assumptions we were asked to start with in preparing the *Briefing* were that carers, care recipients and service providers can share a common pool of knowledge, and given the right tools, the sector as a whole can be a lever for local service development.

Evidence is part of the tool kit, but it has the potential to be just more 'noise' in the system unless it can be translated into practical terms and add up over time to a repository of shared and useful experience, understood in a common language. And one element of knowledge that is 'useful' is that it can put pressure back on central policies and programs to evolve in ways that support the repositories of local knowledge. We hope to take more steps in that direction by participating in the Benevolent Society's series of publications to put our research lessons into a more accessible format.

Practice implications

A consistent theme in the entry point assessment work is that standardised questions and consistent data collection are important for promoting equity and measuring outcomes, but are not sufficient to tailor a personalised response to an individual's needs. Narrative provides the context in which carer and care recipient choices are made. If we understand the person and their characteristics, some considerable number of which are common and we can group them, then we can consider the range of alternative responses available and at what cost to doing something new or some current things better.

A useful care plan requires a home visit and more depth and detail if it is to recognise the attributes (strengths and risks) of the home setting and the experience of the person and any carers requiring assistance.

The type of data collected at the entry point is reasonably well worked out now and a sample set of questions that we know work reasonably well, and can be used to measure outcomes, are included in the attached table.

An illustration of the data elements in carer assessment is shown below and the two components of standardised data and narrative can be used to open up discussion within an individualised approach to assessment.

Key points

The design features of assessment are well described already and the community care field knows how to assess people and are just getting on with doing it. The central policies have been either silent or very confused and progress has been very slow, but that is the result of the division of responsibilities between the Commonwealth and State programs.

In assessment the debate about a 'gateway' has been confused by the distinction between a 'one-stop shop' and a 'no wrong door' approach.

Our experience suggests a distributed network of common tools sharing a system of standardised data elements makes most sense.

A distributed network model can do a good job if there is investment in a central repository and resources for data analysis. That allows us to classify and compare different types of clients (where they have a client type based on their goal of care), so routinely collected data can be used to ask questions about what interventions work best (efficiency) and who is likely to benefit most (outcomes).

This approach implies the use of a common language and a shared understanding of how to assess needs - without a power struggle about who controls the gateway function, or whose software is smarter.

Once we have got an agreed way of collecting useful information and a place to analyse it and feed it back to the aged care sector, then we are in a position to improve quality and the system gets better over time.

Alan Owen
Centre for Health Service Development

Attachment: Examples of well-tested questions for carers – some are useful for understanding resilience, and some for measuring outcomes if collected at re-assessment.

QUESTION/DATA ELEMENT

RESPONSE CATEGORIES/CODES

WHAT WERE THE KEY CIRCUMSTANCES TRIGGERING CONTACT?

Hospital discharge
Recent diagnosis
Falls
Acute medical condition
Carer burden
Concern about increasing frailty
Other
Text

WHAT DOES THE CALLER EXPECT THE OUTCOME TO BE?

ASSISTANCE IS REQUIRED TO:

Improve current level of function and independence after a recent acute illness/event
Improve current level of function and independence (other)
Maintain current level of function and independence
Reduce rate of decline in level of function and independence

Adult Functional Profile

CAN YOU DO HOUSEWORK ...

Without help (can clean floors etc)?
With some help (can do light housework but need help with heavy housework)?
Or are you completely unable to do housework?

CAN YOU GET TO PLACES OUT OF WALKING DISTANCE ...

Without help (can drive your own car, or travel alone on buses or taxis)?
With some help (need someone to help you or go with you when travelling)?
Or are you completely unable to travel unless emergency arrangements are made for a specialised vehicle like an ambulance?

CAN YOU GO OUT FOR SHOPPING FOR GROCERIES OR CLOTHES (ASSUMING YOU HAVE TRANSPORTATION)...

Without help (taking care of all shopping needs yourself)?
With some help (need someone to go with you on all shopping trips)?
Or are you completely unable to do any shopping?

CAN YOU TAKE YOUR OWN MEDICINE ...

Without help (in the right doses at the right time)?
With some help (able to take medication if someone prepares it for you and/or reminds you to take it)?
Or are you completely unable to take your own medicines?

IF NOT WITHOUT HELP, IS REASON

Physical
Cognitive
Both

CAN YOU HANDLE YOUR OWN MONEY ...

Without help (write cheques, pay bills etc)?
With some help (manage day-to-day buying but need help with managing your chequebook and paying your bills)?
Or are you completely unable to handle money?

QUESTION/DATA ELEMENT

RESPONSE CATEGORIES/CODES

IF NOT WITHOUT HELP, IS REASON

Physical
Cognitive
Both

CAN YOU WALK ...

Without help (except for a cane or similar)?
With some help from a person or with the use of a walker, or crutches etc

CAN YOU TAKE A BATH OR SHOWER...

Or are you completely unable to walk?
Without help?
With some help (e.g., need help getting into or out of the bath)?
Or are you completely unable to bathe yourself?

These 7 questions are qualified by
IF THE PERSON HAS DIFFICULTY, WHO HELPS THEM?

No-one
Carer
Service provider
Other

(AND) TO WHAT EXTENT IS THIS NEED MET?

N/A - no need
Fully met
partially met
Completely unmet

DOES THE PERSON HAVE ANY MEMORY PROBLEMS OR GET CONFUSED?

Yes
No

DOES THE PERSON HAVE BEHAVIOURAL PROBLEMS (E.G. AGGRESSION, WANDERING OR AGITATION)?

Yes
No

Comments

Text

Carer/Family

DOES THE PERSON NEED A CARER

The person cannot be left on their own at any time (whether by day or night)

The person can only be left on their own for some, but not all, of the time (whether by day or night)

No Carer required

Paid carer

DOES THE PERSON HAVE A CARER?

Has a Carer

No carer

CURRENT THREATS TO PC - PERSON ARRANGEMENTS?

Not applicable - paid carer

Carer – emotional stress & strain
Carer – acute physical exhaustion/illness
Carer – slow physical health deterioration
Carer – factors unrelated to care situation
person – increasing needs
person – other factors

ARE PC- PERSON ARRANGEMENTS SUSTAINABLE WITHOUT ADDITIONAL SERVICES OR SUPPORT?

No, arrangements have already broken down

No, carer arrangements likely to break down within months

Yes, carer arrangements are sustainable without additional support

Not sure

Comments

Text

Carer Support

DOES PC HAVE SOMEONE TO HELP HIM OR HER?

Yes

No

Not sure

Comments

Text

QUESTION/DATA ELEMENT

RESPONSE CATEGORIES/CODES

Pain

HOW MUCH BODILY PAIN HAVE YOU HAD DURING THE PAST 4 WEEKS?

None
Very Mild
Moderate
Severe
Very Severe

If bodily pain, has consumer seen a health professional about this problem?
If not, is a referral warranted?

Yes
No
Yes
No

Comments

Text

Falls

HAVE YOU HAD A FALL IN THE PAST 6 MONTHS?

Yes
No
Not sure
Number
Text

If Yes, record number of falls ...
... and what was the outcome?

Nutrition

HAVE YOU LOST WEIGHT RECENTLY WITHOUT TRYING?

Yes
No
Not sure

The Future

DOES THE PERSON OR PARENT/CARER HAVE ANY CONCERNS FOR THE PERSON'S FUTURE?

Yes
No
Not sure
Text

Comments:

ARE THEY OR PARENT/CARER ABLE TO IDENTIFY ANY GOALS FOR THE PERSON THAT THEY WOULD LIKE TO ACHIEVE IN THE NEAR FUTURE?

Yes
No
Not sure

Comments:

WHO ASSISTS WITH FINANCIAL DECISIONS OF THE PERSON?

No-one
Significant Informal Assistance
Power of Attorney
Parent or Guardian
Formal Financial Administrator or Manager
as much as I wanted
quite a bit
some
a little
not at all

DURING THE PAST 4 WEEKS, WAS SOMEONE AVAILABLE TO HELP THE PERSON IF THEY NEEDED AND WANTED HELP? FOR EXAMPLE IF THE PERSON -FELT VERY NERVOUS, LONELY OR BLUE -GOT SICK AND HAD TO STAY IN BED -NEEDED SOMEONE TO TALK TO

Yes
No

ASSESSOR, IF NOT AT ALL OR A LITTLE ASK "DOES THE PERSON USUALLY HAVE ENOUGH SUPPORT?"

Comments

What sorts of social activities is the person involved in outside the home?

Text

Does the person have a range of friends outside of home?

Yes
No

What are his/her usual leisure activities, and hobbies?

Text

QUESTION/DATA ELEMENT

RESPONSE CATEGORIES/CODES

Are they involved in

Education

Employment

Other activities- please specify number

and for how long usually per week?

Comments

Yes

No

Not sure

Would the person be interested in finding out about... Assessor, provide relevant examples, e.g. information about relevant services including social support for the family

Comments:

Text

Zarit Carer Screen (Australian Modified 4 item version)

Scoring for 4 item version only

Do you feel that because of the time you spend with CR that you don't have enough time for yourself?

(1) Never

(2) Rarely

(3) Sometimes

(4) Quite frequently

(5) Nearly always

Do you feel stressed between caring for CR and trying to meet other responsibilities for your family or work?

Subtotal

Do you feel strained when you are around CR?

Do you feel uncertain about what to do about CR?

Total

Assessor: If total score is 5 or more, consider completing the 12 item version of the full 22 item Zarit Carer Screen.

Comments

Text

Zarit Carer Screen (Australian Modified 12 item version has 8 additional items)

Scoring of 12 item version for all questions

Do you feel angry when you are around CR?

0 = Never

1 = Rarely

2 = Sometimes

3 = Quite frequently

4 = Nearly always

Do you feel that CR currently affects your relationship with other family members or friends in a negative way?

Do you feel your health has suffered because of your involvement with CR?

Do you feel that you don't have as much privacy as you would like because of CR?

Do you feel that your social life has suffered because you are caring for CR?

Overall level of stress using the 22 item version suggested by Total scores:

Do you feel you have lost control of your life since you began caring for CR?

0-20 = Little/No Stress

21-40 = Mild/Moderate Stress

41-60 = Moderate/Severe Stress

61-88 = Severe Stress

Do you feel you should be doing more for CR?

Do you feel you could do a better job in caring for CR?

Comments

Text